

Deaf and Dying

Communicating with people at the end of life who are deaf or hard of hearing



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Just over 500,000 people die in England and Wales every year. Current evidence is that 1 in 7 of us is deaf or hard of hearing. This would suggest that of those ½ million people dying each year, over 70,000 will be deaf or hard of hearing. Yet there is very little deaf awareness within the world of palliative care.

At such a time, deaf people will need the best means of communication they can access. But a family interpreter or third party will not always be appropriate and providers of palliative care must bear this in mind when dealing with patients at this stage in their lives.

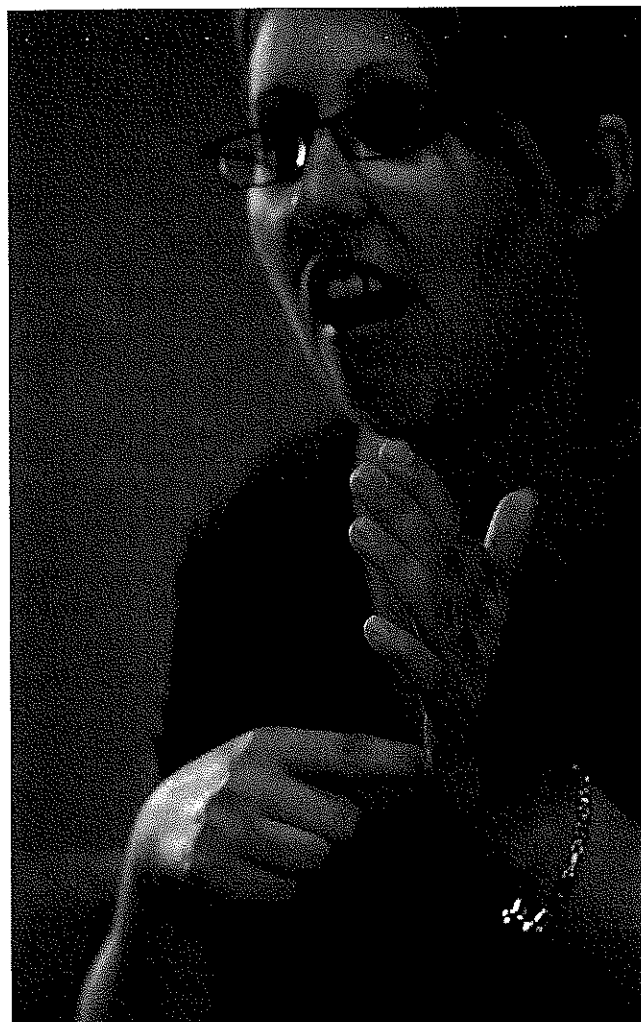
"I prefer an interpreter because they will interpret fully what's happening. Family or friends only give a summary or what they think you want to hear"

SignHealth recently published a report into deaf people's access to primary health

care and their report "Why do you keep missing me?" [SignHealth 2008] highlights evidence that deaf people are unhappy with certain aspects of health care and that deaf people are markedly less healthy than their hearing peers.

35% of deaf people are unclear about their diagnosis or condition because of communication problems and where the diagnosis is around a serious condition, any delay can of course be serious or fatal.

40% of deaf people will experience mental health problems. This is twice the rate seen in the hearing population. Depression is common within the deaf population and we know that depression is also common amongst people with a life-limiting diagnosis.



There is a major misconception that deaf people can communicate through the written word - but this is just not true. For most profoundly deaf people, English is not their first language and, just as many of us have no understanding of foreign languages written or spoken, deaf people will struggle with English. They will often lack general knowledge about physical health and all the information that we pick up subliminally through TV, radio and newspapers. Combine this with the fact that the public are generally reluctant to

talk about death and dying, and information about the end of life for a deaf person will normally be a complete unknown.

Some deaf people can lip read but only 40% of speech is actually lip readable and very few people know how to help maximise lip speech by facing the deaf person and sitting without ambient light behind them.

"I see an oncologist who will not look at me when he's speaking - he always turns to his computer screen or looks down at his notes - I could scream!"

This all presents a huge challenge to palliative care professionals, for whom communication is a vital tool for managing end of life. People need to have a complete understanding of their diagnosis and what lies ahead for them, and they need to be able to verbalise their fears and concerns as well as plan for their families. If it is not the patient but a family member who is deaf, then the holistic approach adopted by most hospices and other palliative care professionals must extend to their communication needs as well.

There is a national shortage of BSL interpreters for sign language users. It is estimated that there are around 70,000 people for whom BSL is their first language. There are only 400 qualified BSL interpreters and their locations are geographically sporadic, so getting an interpreter for a same day consultation or discussion is very unlikely. The day to day health of people at the end of their lives will change rapidly and therefore good, prompt communication is vital to the quality of life in this period.



In response to this unmet need, SignHealth, the healthcare charity for deaf people, has developed SignTranslate, an on-line interpreting facility which means that immediate translation is available when and where the patient needs it. The program is free to all health services and the interpreting fees represent a significant cost saving on face to face translation.

There are also some simple deaf awareness techniques that can make a great deal of difference to the understanding of both patient, family member and professional.

"I'm 30 years old now and I still have nightmares about being used as an interpreter in the hospital to tell my

beloved Deaf father that he had terminal lung cancer. I was 9 years old. A month later, I interpreted at his funeral"

Professor Mayur Lakhani, NCPC's chairman, said "Providing quality of life for all at the end of life is the hallmark of a caring society" We agree - just don't forget to include the deaf and dying.

More information

For more information on deaf awareness or to see how SignTranslate can make a difference to deaf communication, contact Rowena Dean at SignHealth or visit our website at www.signhealth.org.uk